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This month I attended Planetnetwork, a three-day meeting in San Francisco on new online tools for social organizing, to improve civil society and allow people around the world to work together for common projects and goals. Over 100 presenters told of many

AIDS Treatment News

Subscription and Editorial Office:

AIDS Treatment News
Philadelphia FIGHT
1233 Locust St., 5th floor
Philadelphia, PA 19107
800-TREAT-1-2 toll-free U.S. and Canada
fax: 215-985-4952
email: aidsnews@aidsnews.org

Editor and Publisher: John S. James

Reader Services: Allison Dinsmore

Statement of Purpose:

AIDS Treatment News reports on experimental and standard treatments, especially those available now. We interview physicians, scientists, other health professionals, and persons with AIDS or HIV; we also collect information from meetings and conferences, medical journals, and computer databases. Long-term survivors have usually tried many different treatments, and found combinations that work for them. *AIDS Treatment News* does not recommend particular therapies, but seeks to increase the options available.

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important experiments and a few spectacular successes -- mostly unknown in the AIDS world today. These advances will change how we live and work, and AIDS activists and organizations will benefit by knowing about them and taking a lead in exploring how to use this work to help solve problems we face. This article is the first of three reports on these developments that *AIDS Treatment News* will publish over the next few months.

Major Scientific AIDS Conference, Paris July 13-16; Reports Online

The 2nd IAS Conference on HIV Pathogenesis and Treatment will take place July 13-16, 2003, in Paris. This conference is organized by the International AIDS Society (IAS), which also puts on the International AIDS Conference, which happens in even-numbered years (the next one will be near Bangkok, Thailand, in July 2004).

The Paris conference has been called "the international forum that brings together scientists and clinical researchers working on HIV/AIDS from both the developed and developing world, forging alliances to jointly address the most pressing issues in the combat against this global emergency" (quote from Professor Joep Lange, chairman of the International AIDS Society). [Note: the International AIDS Society should not be confused with the International AIDS Society-USA, an unrelated organization.]

The final program of the Paris conference was posted June 30 at <http://www.ias2003.org/>. The 360-page

document (a 3 megabyte file) can be searched on your computer for a keyword or phrase, such as a medical term, drug name, or presenter's name.

Two official Internet providers for the conference are noted on page 15 of the program:

- * Kaisernetwork.org will provide Webcasts of the plenary talks and some of the other major sessions. You can find them at:

<http://www.kaisernetwork.org/paris2003>
or through the IAS Web site above.

- * Medscape will provide conference coverage and continuing medical education programs based on this conference. See:

<http://www.medscape.com/hiv>. Note: free registration is required.

On June 30 Medscape said its coverage will include "daily news and expert commentary; an executive summary of the conference that will be published within one week of the conference's close; and a series of approximately 15 topical reviews, which will be available to physicians for continuing medical education credit, that will be published within 3 weeks following the meeting. Slide kits and slide-based presentations of selected conference sessions will also be published on Medscape at that time."

New Protease Inhibitor Atazanavir (Reyataz™) Approved

On June 20 the FDA approved the new once-a-day protease inhibitor atazanavir (brand name Reyataz), manufactured by Bristol-Myers Squibb. Atazanavir has little effect on the blood lipids cholesterol and triglycerides, and on May 13 the FDA's advisory committee of outside experts had unanimously recommended approval (see *AIDS Treatment News* #391, May 30, 2003). Atazanavir can be taken as two pills once daily with food. In patients who have already had extensive HIV treatment, atazanavir may need to be "boosted" with a low dose of ritonavir (Norvir®) to maintain atazanavir blood levels (a reduced dose of

atazanavir is recommended in this case; see Web site below to check current information). As with all other current antiretrovirals, atazanavir must be used as part of a combination regimen.

The advisory committee had some concern that the FDA was not be able to review all the data on treatment-experienced patients before the legal deadline for drug approval.

On June 20 Bristol-Myers Squibb, the manufacturer of atazanavir, issued a press release including the following cautions:

"Do not take REYATAZ if you are taking the following medicines: ergot derivatives, Versed(R), Halcion(R), Orap(R), Propulsid(R), Camptosar(R), Vascor(R), Crixivan(R), Mevacor(R), Zocor(R), Rifampin, St. John's wort, AcipHex(R), Nexium(R), Prevacid(R), Prilosec(R) or Protonix(R). [Not a complete list -- JSJ] Do not use Viagra(R) while you are taking REYATAZ without first speaking with your healthcare provider. Discuss all prescription, non-prescription and herbal products you are taking or plan to take with your healthcare provider.

"Increases in indirect bilirubin (bilirubin is made by the liver) have been reported in patients taking REYATAZ. This may result in yellowing of the skin and/or eyes. These symptoms usually go away after you stop taking REYATAZ.

"Changes in the way your heart beats may occur when taking REYATAZ. If you get dizzy or lightheaded these could be symptoms of a heart problem. An increase of lactic acid in the blood (lactic acidosis), which can cause death, has been reported in patients taking REYATAZ with other anti-HIV medicines called nucleoside analogues. In some patients taking protease inhibitors, increased bleeding (in patients with hemophilia), diabetes and high blood sugar have occurred. If you have liver disease, including hepatitis B or C, your liver disease may get worse when you take anti-HIV medicines like REYATAZ."

For a current copy of the atazanavir "labeling" (information for doctors), see the full prescribing information at <http://www.reyataz.com/>. Always use a current copy of the prescribing information, especially for a newly approved drug, since it will change as new information becomes available.

Federal AIDS Policy Emergencies

by Kate Krauss and John S. James

Members of ACT UP Philadelphia have begun to track the numerous federal cutbacks and policy changes affecting U.S. AIDS services and are assembling a list in a single document. Crucial programs such as Social Security disability, ADAP, Medicare, HIV prevention, and biomedical research are all currently under fire.

We are preparing lists of organizations that publish quality action alerts on these issues, and would appreciate recommendations.

ADAP (AIDS Drug Assistance Program)

Fifteen states including New York have instituted waiting lists or other access restrictions; six others are expected to implement restrictions soon. Activists estimate that at least 12,000 people with HIV who need this program cannot access it this year -- in many instances this means that people who need HIV treatment will not be getting it at all. Unless Congress passes an emergency-spending bill for the ADAP, the situation will only grow worse until March 31, 2005. See AIDS Treatment Data Network for more information <http://ATDN.org/>

New Social Security Disability Definition: Public Comments Deadline July 8

The definition of who is "disabled" due to HIV infection was last revised in 1993, and is being updated to reflect modern treatment. You can see the proposed definition (and submit public comments) by visiting:
http://www.ssa.gov/disability/newrules_immunesystemdisorders.htm
You can also read comments already submitted by others.

[Note: If this link does not work, try visiting <http://ssas.com>, then click on Connect Board, then click on Listings, then scroll down to Immune System listings.]

What we have heard from people involved is that this is a legitimate effort to update the rules for modern conditions -- but there are concerns. One problem is that government works through lists of diagnoses, and tries to save money. But what we most hear from individuals is that they can work either part time or full time, but do not know how long that will continue. They need to be able to go back to work without losing their benefits, and then being destitute and without medical care if they lose their job.

Another problem is that the new rules may give officials many more occasions to call people in for hearings that can revoke their benefits. Such procedures have been abused in the past to remove people who are clearly disabled, just to save money. Also, a large increase in hearings and revocations would complicate financial and medical planning, which can be very difficult already.

Medicaid

Medicaid provides healthcare, including prescription drugs, for low-income, elderly, and disabled people including about 260,000 people with AIDS. The largest federally funded healthcare program for people with AIDS, it is also typically the second largest state budget item after education. But the depressed U.S. economy has reduced tax revenues and many states are running huge deficits.

In response, dozens of states are attempting to save money by lowering the maximum personal income allowed for eligibility, dropping hundreds of thousands of "optionals" (people who meet slightly relaxed eligibility requirements) from Medicaid rolls, reducing access to prescription drugs, and eliminating access to nursing home care and other services. In Texas, for example, disabled patients cannot earn more than \$552 per month to qualify for the program. In South Carolina, the governor is planning to reduce the maximum number of prescriptions per month from 4 to 3. In California, the governor attempted to de-fund hospice care this year until aggressive public policy advocacy by the hospice community restored the money. Many states have instituted highly restrictive Medicaid drug formularies, effectively putting expensive drugs out of reach for many people with AIDS.

Advocates succeeded in pushing Congress to

disburse \$10 million directly to Medicaid through a temporary increase in the Federal Medical Assistance Percentage, but that is a small part of the shortfall.

In addition, President Bush is aggressively advocating for a plan that would limit federal contributions to the program regardless of a state's costs. Such a plan would encourage states to further reduce benefits and establish obstacles to patient care in the interests of cost containment. A state-by-state list of Medicaid cuts is available from TIICANN at 202-588-1775, or by emailing Tom McCormack: tomxix@ix.netcom.com. Families USA has information on both Medicaid and Medicare, <http://www.familiesusa.org/>.

Medicare

Medicare provides health care (but not prescription medications) for many people with AIDS. Prescription coverage plans that have been approved by Congress will not be fully implemented until 2006 and will require recipients to spend \$3,500 (in the House version) to \$3700 (in the Senate version) out of pocket before catastrophic coverage kicks in (either 90% in the Senate version or 100% in the House version). (People with incomes of \$60,000 or higher would have to pay more out of pocket before catastrophic coverage takes effect.) U.S. drug regimen costs for people with AIDS start at about \$10,000 and can total \$30,000 or more per year. In states where the AIDS Drug Assistance Program is weak and patients do not also qualify for Medicaid, these costs will mean that people with AIDS cannot afford their medications. A compromise between the House and Senate versions of the bill is expected to be reached in conference committee later this summer.

Families USA offers important updates on Medicare: <http://www.familiesusa.org/>. The Kaiser Family Foundation also has an important information source on Medicare: <http://www.kff.org>.

Prevention

The U.S. Centers for Disease Control (CDC) instituted far-reaching changes to its prevention policy and funding priorities in April 2003 in an effort to remove barriers to testing and care. Programs to test more people, get those who are HIV-positive into treatment and care, and help them prevent transmission to others are widely supported.

Unfortunately the CDC will greatly reduce or discontinue funding support groups, safe sex workshops, and other programs to help those who are high risk and HIV-negative protect themselves. Organizations that provide primary prevention, including many groups that target people of color, will get much less funding under this plan.

The CDC now promotes widespread, routine testing in doctors' offices, prisons, and among pregnant women -- but will no longer promote specialized counseling for those who are tested. And while this testing will find more people who test positive, the agency has not allocated more money for counseling and care.

The CDC has also changed its practices under pressure from conservative critics who do not like gay-friendly AIDS organizations. Last fall, the CDC audited several groups that participated in a protest against HHS Secretary Tommy Thompson at the 2002 Barcelona International AIDS Conference. The CDC cited federal funding of the groups to justify the audits, but many activists saw them as retribution for the protest. New York's Gay Men's Health Crisis and the African Services Committee were among those audited.

The CDC is also cracking down on AIDS organizations that use sexually explicit materials, and on June 13, 2003 sent a letter to San Francisco's 19-year-old Stop AIDS Project accusing the group of breaking a federal law that prevents federally-funded organizations from encouraging or promoting sexual activity. Ironically, the organization had recently passed audits (also a result of pressure from right-wing conservatives) by the Office of the Inspector General and the CDC. The audits determined that Stop AIDS programs were

adequately supervised by the San Francisco Health Department and were in keeping with community standards.

Conservatives are also influencing scientific research at the CDC: research grant applicants are now discouraged from using standard terms to describe the populations and behaviors they plan to study (men who have sex with men, anal sex, etc.).

Serious Cut in Basic Biomedical Research

In a last-moment bureaucratic move, the Bush Administration's Office of Management and the Budget (OMB) ordered the National Institute of Allergy and Infectious Diseases (NIAID) to spend \$233 million on a bulk purchase of anthrax vaccine. The result is that over \$200 million must be taken away from basic research in HIV, other infectious diseases, and immunology. Congress had not appropriated funds for the vaccine purchase, apparently because it thought that this money should not come from the NIAID research budget but from other government channels, and the Administration had not requested the money in those budgets.

Even without the diversion, only about 25% of NIAID grants judged scientifically worthy would have been funded. With \$233 million taken out, only 18% will be funded. No one knows ahead of time which of the projects may turn out to be critically important.

The pharmaceutical industry does very little basic medical research because of lack of commercial incentive. Instead, it relies on the Federal government to fund researchers at universities and other institutions. As a result, the studies rejected due to the diversion of funds will be delayed or not done.

Nature, considered by many to be the world's most prestigious scientific journal, called this case "a prime example of how centralized control could undercut the NIH's mission of protecting the health of the United States and the world" ("Biodefence Takes Its Toll," *Nature*, June 5, 2003, issue #423).

AIDS, Computers, and Organizing: Part I, Toward a Revolution in

Fundraising? A Report from the Planetnetwork Conference

by John S. James

Recently I attended Planetnetwork, a three-day conference in San Francisco on new ways of using computers and online technology to help people work together for a better future¹. Some new communication and organizing tools, many available now, could make a big difference in AIDS and health. I have a background in computers and was the only AIDS writer there, and will report to the community on some of this new work, and why it is important for us.

Over 300 people, some from as far as London, heard 100 presenters, many of them well-known leaders in the computer industry, in three parallel meeting tracks. The conference was supported by registration fees and by industry partnerships, mostly with small technology companies.

This article will look at software for extending existing social networks, as a way to help people around the world work together on common goals and projects -- even when some of them have no computer, email, or Web access.

Online Social Networks -- and Fundraising

A key theme of the conference was establishing trusted communication online, to assist existing networks of friends and colleagues who already work together and trust each other. A semi-official "white paper" for the conference (*The Augmented Social Network: Building Identity and Trust into the Next Generation Internet*) explored some of these ideas². "Trust" in this case refers to personal judgment, especially knowing someone and having confidence that you can recommend him or her to associates for a working relationship.

To show what augmented social networks could mean for AIDS, here is a fundraising scenario we expect to be happening within a few years. The software required either exists today or could easily be written. What will take time is for people to learn about this possibility and start using it together.

For this example we will take a hard problem -- raising money for local AIDS and health clinics and other grassroots projects in developing countries. But the same tools could work for many purposes.

It is well known that small amounts of money can save lives or otherwise make a big difference in poor countries (see the new documentary film, *A Closer Walk*, <http://www.acloserwalk.org/>). Today almost all money donated goes through governments, big nonprofits or churches, or other large organizations. For some projects this is the best or only way to proceed. But many people would be more willing to give directly through a personal connection. (We suspect that these two kinds of giving will be more synergistic than competitive -- that if donors had good ways to give directly they would become more personally involved, leading to more political will to support government, nonprofit, and church programs, rather than less.)

The problem today is that the people and personal networks who can donate are far away, both geographically and socially, from the people and personal networks where their money could do the most good. Most potential donors living in the U.S., for example, do not know anyone in any developing country -- especially in remote villages where many of the people live, and where a little money could often go farthest. And most donors today do not personally know who is really doing the most important work, but must rely on public relations and carefully crafted images, which they know very well are unreliable -- discouraging commitment and contributions. On the other side, those who have the first-hand knowledge usually have no good way to reach many donors and establish credibility.

How could computers help? Imagine that a few years in the future, you hear that \$25 could save a life in poor areas through health care or famine relief (as is the case today). Perhaps you want to make a small contribution directly to an organization or person on the scene -- for example, a local group somewhere in Africa that is doing superb work but may not be part of any big charity or international organization. You want to contribute based on the personal recommendation of someone you trust. Usually there are people you trust -- but none of them are at the scene, so they cannot help you directly.

So instead of making dozens of phone calls to try to find a chain of recommendations that reaches from your personal network into villages in Africa, you go to a social-network Web site where basically anyone in the field (global AIDS or health in this case) could publish a profile for themselves -- including a list of people or groups they recommend.

For example, since you are reading this newsletter, perhaps you trust me. I do not know who in poor countries could best use your contribution -- but I do know well-regarded doctors, activists, and others who work or volunteer there, whose judgment and recommendations I trust. Perhaps none of them know what is really happening on the ground in a particular area, but they are closer than you or I, and will know people closer still.

Health activists and professionals who work regularly in developing countries could create a profile of themselves on a social-network Web site for international AIDS, or international health. Their profile would include a list of individuals and organizations that they recommend as doing good work -- and who could also put their own profiles on the site, where they list others they recommend. Those listed need not have access to computers, nor speak English or whatever language is used on the site, because their colleagues who want to recommend them and help raise funds could work with them to prepare and submit their profiles. These profiles might include specific projects that need doing, with a budget for each.

At the simplest level, the way social-networking programs work is that you can click a link on anyone's profile to see their network of friends or trusted colleagues. Then you can click on any of those profiles to see that person's network, etc. Just with this much, you could start with one person or several people you trust, then check through the networks partly by trial and error to get closer to the kind of project you are looking for -- either geographically (Africa, for example), or by other categories. But software tools (discussed below) could greatly help.

Networks of personal recommendation have always been important in almost every human activity. But usually it is difficult in personal networks to go through a chain of more than two or three referrals -- especially across international borders, time zones, and language

barriers, or into regions that have no telephones, computers, or other modern communication. Even when communication is possible it is not feasible to make dozens of phone calls in different languages to explore social networks and establish a trusted chain of referrals, all for the sake of perhaps a \$25 contribution.

But with a social-network Web site, potential donors or anyone else can explore these personal and professional networks whenever they want -- without necessarily setting up their own profile or making any other arrangements in advance. They can start by finding one or more people they trust who have profiles on the site, and then look for chains of trusted referrals to projects they want to support.

I would guess that in a specialized area like global AIDS, the average length of the shortest personal-referral chain from, for example, an interested U.S. citizen to a clinic or other project in a village in Africa, would be less than the proverbial "six degrees of separation," but more than the two or so degrees that can comfortably be managed informally. The first time a potential donor uses this system, he or she might spend an evening exploring the links through these social and professional circles, looking at perhaps several dozen of the thousands of profiles on the site, to find one or more chains of perhaps three, four, or five connections that work for them -- ending with an organization or individual they want to help. Since part of the work of setting up the Web site would be to provide a way that funds could be transferred legally, inexpensively, and conveniently, with a few keystrokes the donation could be done. Each recipient organization, individual, or agency would have a way to be notified that the contribution had arrived and credit was available; that would be part of their profile. They would also be able to contact and thank the donor and tell how their contribution was used, unless the donor asked not to be identified publicly.

Advantages to Consider

* In AIDS we already have networks built on personal trust and long-time working relationships, and these function well. But we need better ways to connect the separated networks, so that they can coordinate better when appropriate. Social-network software -- especially databases of personal and professional recommendations, within a given field or for a particular purpose -- could

support larger projects and activities, without the problems of a centralized, top-down command structure (which has not worked well in AIDS).

* Speakers at the Planetnetwork conference were quite familiar with academic studies of social networks, at Stanford University and elsewhere. One of the findings has been that important benefits like learning about a new job are more likely to come from loose social connections (for example, an acquaintance of a friend) than from tight connections (being part of the same corporation, school, or other social structure). Social-network software extends these loose connections.

* Software tools can help in searching the network for a credible chain of recommendations. For example, a potential donor could list any number of profiles of people or organizations they trust, as a starting point -- and also list any number of potential recipients, as a goal -- and ask the system to find any connections automatically. They could also specify potential recipients either geographically (all organizations in Africa, for example), or by kind of mission (such as caring for orphans), or both -- and then find the chains of trusted links and list them by strength of the connection. Searches could also specify keywords, names, or subject areas in the profiles. The software could also show who throughout the whole database recommends a particular project or organization. Other tools could allow users to click to see a visual picture of the whole social-network database, showing how much it is a unified network vs. a collection of separate groups -- and if the latter, then who are the crucial links between the groups. Potential donors could use their choice of such software tools, or just follow links one by one to find groups they want to support.

* Potential recipients (and others in the database) can speak any language, and do not need to have access to computers -- since those who are recommending them will be motivated to help them enter their project description and other profile information.

* The profiles could belong to individuals or to organizations interchangeably (in that the system handles them the same in either case, although potential donors can specify one or the other in their data searches or views). Profiles could also belong to other entities, including software robots (computer programs